

I am the mother of a wonderful 21 year old son who has autism. His name is Andy. I will describe his situation for you, but I want to emphasize that I am writing not just out of concern for my own son and family, but also out of concern for anyone who is in a similar set of circumstances.

Andy was diagnosed with autism just before his third birthday. He has had special education since age 3, and just aged out of the school system this past June. His last two years of public education were at the Manchester Transition Center. He loved school, and misses it very much.

The worst aspect of Andy's disability is his language disorder--it is very serious. His language ability is in the bottom 2%, and it took years of intervention to get it that good. This affects every aspect of his life: He has limited understanding of what people say to him, and his ability to express himself is also limited. The potential for serious social misunderstandings always exists, so he generally does not go out unaccompanied. He only reads on a third grade level, so higher education is out of the question. Andy can learn (mostly visually), but does not have the ability to be a self-directed learner. He isn't able to plan for his future, handle his own finances, or make his own medical decisions. He will most likely never drive, because in addition to the complications caused by his autism, he also lacks acute vision in his right eye. My husband and I are conservators of both his person and estate.

In spite of all the above, Andy's full-scale I.Q. measures in the low 70's, so he is not considered intellectually disabled, and he does not qualify for services from DDS.

Andy is eligible and supposedly on the waiting list for services from the DDS Autism Division. A month before he aged out of the school system two ladies from the Autism Division visited us at our home mostly for the purpose of telling us that there is nothing they can do for him because "there's no money, and no slots are opening up in the foreseeable future." I asked them if they could at least tell me where he is on the waiting list, and they told me it didn't matter because "nothing is opening up".

For years, parents who attended various autism-related support groups were given the impression that the Medicaid Waiver would make support services for adults with autism much more widely available, but apparently this is not how things turned out. Under the Medicaid waiver, the Autism Division provides services to a relatively small handful of people, and everyone else with the exact same diagnosis is on a waiting list indefinitely, waiting for people who are receiving services to transition out of the program. Personally, I think it is unlikely that any people who are getting help under the waiver will EVER transition out, unless they die. Autism is a life-long disability, and most people afflicted with it will need life-long support services. The number of slots need to be expanded. The state has a moral responsibility to find a way to do this!

BRS is currently working with Andy to try to help him find a part-time job. Even if he finds employment, it is unlikely that he would ever be self-supporting. Most of his time is spent with me, his mother, trying to teach him life skills, reinforce life skills he already has, exercising with him, and generally supervising him to keep him from spending his entire life watching Youtube clips. He has no typical friends, and any social activities in which he takes part or lessons he might take have to be specially supervised, so of course they are more expensive than the activities of typical people. Andy is vulnerable and naive, so he can't just go off on his own. I love Andy very much, but I never anticipated that at age 54 my full time job would be herding around my 21-year-old son trying to keep him from completely stagnating. It is not a happy situation for him either, and he doesn't hesitate to tell me so! He is just smart enough to

know that his life is very different from most guys his age, but he doesn't really understand why. He is often frustrated by this.

I have communicated these concerns to various people who work for DSS and DDS, but they say there is nothing that can be done unless the legislature takes action to appropriate additional funding for the Autism Division of DDS so that they can provide services for more people. Autism is a very serious, lifelong disability, and the people afflicted with it need support, and they deserve it every bit as much as the mentally ill, the intellectually disabled, recovering drug addicts, etc. The state government needs to take it seriously. There has been a lot of focus on services for young children with autism, who already get considerable services from their school systems through the IEP process. Autistic children grow up to be autistic adults, and many autistic adults are receiving no services at all.

I understand that the state has a lot of economic problems, and I was alarmed to read about the deficits projected starting in the 2015-2016 fiscal year. If nothing is done for people with autism now, what chance will there be when these big deficits kick in?

I think it would be an expenditure that even the most fiscally conservative person could understand---I doubt that there is anyone left that does not know at least one family that is struggling with autism in some way; it is a public health disaster. and no one knows why it is happening.

One of the state officials I contacted wrote: "We recognize that this (care of adults with autism) is one of the hardest issues we face today in the health care field:" Great... so we "recognize" that--- is it enough to just acknowledge that and not do anything about it? Once again I ask: Is anyone in the state government looking for solutions? This issue is not just going to go away if we ignore it.

Thank you for taking the time from your busy day to read this. I really appreciate it.

Sincerely,

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